STATE OF WASHINGTON

WASHINGTON STATE BOARD OF HEALTH

1102 SE Quince Street • PO Box 47990
Olympia, Washington 98504-7990

Minutes – April 12, 2002 Genetics Task Force Meeting

The Washington State Board of Health Genetics Task Force (GTF) convened its third meeting on April 12, 2002 at the University of Washington Campus in Walker-Aimes Hall in Seattle, Washington. Linda Lake, Genetics Task Force Chair, called the meeting to order at 9:26 a.m. Task force members introduced themselves for the audience in attendance. Chair Lake explained the purpose of the task force for the audience. Chair Lake asked task force members to send comments on/requests for changes to February 25th minutes to Candi Wines (candi@nobounds.com).

The following Board of Health Genetics Task Force members attended the meeting:

Linda Lake, Chair
Maxine Hayes, M.D., M.P.H.
Bob Miyamoto, Ph.D.
Maureen Callaghan, M.D.
Robin Bennett
Melanie Hughes, J.D.
Peter Byers, M.D.
Nancy Fisher, M.D., M.P.H., R.N.
Ty Thorsen
Phil Bereano, Ph.D.
Amanda DuBois, J.D.
Joe Finkbonner

The following Board of Health Genetics Task Force staff attended the meeting:

Don Sloma, Board of Health Executive Director
Desiree Robinson, Executive Assistant to the Board
Jennifer Dodd, Assistant to the Board
Candi Wines, Genetics Task Force Coordinator
Amanda Sarata, Genetics Task Force Assistant

The following invited speakers attended the meeting:

Dr. Jonathan Tait, M.D., Ph.D., University of Washington
Dr. Kenneth Thummel, Ph.D., Institute for Public Health Genetics
Dr. Karen Edwards, Ph.D., Center for Genomics and Public Health
Ms. Amy Klein, M.P.H., Association of State and Territorial Health Officers
Mr. Eric Earling, Director of Public and Government Affairs, Washington Biotechnology and Biomedical Association
Dr. Steve Gilbert, Ph.D., Association of State and Territorial Health Officers
Dr. Bruce Montgomery, M.D., Ph.D., Chief Executive Officer Corus Pharma Inc.

DISCUSSION I: FUTURE DIRECTIONS OF ACADEMIC AND BASIC SCIENCE RESEARCH IN HUMAN GENETICS

Panelists:

- Jonathan Tait, M.D., Ph.D., Associate Professor in the Departments of Laboratory Medicine, Medicine, Genetics and Pathology, Director Molecular Diagnostics Laboratory, University of Washington Medical Center
- Kenneth Thummel, Ph.D., Professor Department of Pharmaceutics, Deputy Director Institute for Public Health Genetics

Jonathan Tait, M.D., Ph.D.

Dr. Tait testified that genetic tests are one of the first "fruits" of genetic scientific advances. They have some drawbacks but are seen as very important and useful to the public. He addressed the question of how genetic tests enter clinical practice today. First, scientists publish basic gene information (the gene's sequence and allele frequencies and disease associations). In response, clinical labs develop 'home-brew' tests (tests based on reagents and procedures developed within a laboratory, not an FDA-approved test purchased from a manufacturer). The public at large depends on laboratories to turn these tests into something that is available clinically. Tests are then offered as a clinical service. Laboratories are licensed by federal and state agencies; approval is not currently required on a test-by-test basis. The public relies predominantly on those tests developed within laboratories and for these tests; clinicians need access to normal and variant samples for controls.

Dr. Tait proceeded to answer the questions on the agenda. He stated that the biggest barrier to developing and offering tests is patenting. The sequestering of the tests in the private sector has implications for their accessibility and affordability. He noted that there is a need to balance the protection of individuals' privacy with the development and improvement of genetic tests. He explained that within a clinical laboratory, the risk to individual patients is small because samples are usually used to test new methods for detecting the same mutations identified by earlier methods. Samples used to gather new information are subject to human subjects/IRB requirements. Dr. Tait noted that only a small sub-set of basic science information would result in clinically useful diagnostic tests. Therefore, research must continue full force to yield appropriate, meaningful diagnostic tests. Dr. Tait commented on the importance of maintaining the availability of genetic material for research. The availability of samples, the regulatory environment and patents all work to limit the progress of basic research. He suggested that there are things that can be done at the state level to mitigate the negative effects of federal patent laws. Dr. Tait suggested that one research priority is to provide high quality, clinically useful testing in a cost effective manner. Genetic tests have the potential to be misused or overused, but there are still major benefits to the public when these tests are provided as part of a comprehensive health care system.

Questions/Discussion

Dr. Bereano asked if, in the development/use of genetic tests, obtaining informed consent hindered the progress of the test development. Dr. Tait answered that, generally no. However, there are instances in which researchers are looking for control samples and can't get them. Control samples are those known to be normal or known to have a specific mutation that are used as a measure of the reliability of the test. As a practical matter, due to the rarity of some mutations, getting consent from controls is sometimes difficult. Dr. Bereano asked if researchers should be allowed to use samples without informed consent, is it necessary for research. In response to the question, Dr. Thummel described two types of sample banks: 1) an anonymized bank and 2) banks in which samples are linked to identifiers because of the value of the samples in the context of the individuals who donated the samples. He stated that there is no problem with using anonymized samples without specific consent and this is generally permitted by the IRB. He noted that IRBs are generally unwilling to allow the researcher to ask subjects for blanket approval, when identifiers are maintained. Dr. Bereano asked if the IRB was the main barrier to using identified samples for non-specified research. Dr. Thummel indicated that yes, the role of the IRB is to protect human subjects. Informed consent increases the burden on researchers, but in most cases it is a justified and reasonable burden.

Dr. Scott inquired about whether there was any reason to treat samples differently based on the testing methodology used in the laboratory. Dr. Tait responded that usually there is no reason to treat samples differently; clinical information is the same even though the testing methodology is different. Dr. Scott asked if there should be a different informed consent process for different testing methodologies when they essentially reach the same clinical endpoint. Dr. Tait replied that there should not generally be different requirements. However, if some tests have different consequences, then those should have a different informed consent process. The consent process should be based on the use of the information, not the analytical procedure.

Dr. Fisher asked about a scenario in which an individual was having a test for Sickle Cell disease. Is it possible that the blood sample taken for one purpose could be used to extract DNA? Has the blood been altered in any way to prevent extraction of DNA? Dr. Tait indicated that the sample in such a case usually has not been altered. He explained that usually the lab extracts the part of interest, and throws away the rest, which usually is the part that contains the DNA. He indicated that some laboratories retain samples because people may want retesting. So in theory, they could generate further additional results on samples; but ethics, and professional guidelines etc., prohibit this. Also, in the case of research, the IRB guides the appropriate future use of samples. Dr. Tait commented that the law does not generally rule these issues. Chair Lake asked for clarification that it is the lab's policies and procedures that govern the use of samples and not really the law. Dr. Tait responded that perhaps some laws might regulate this, such as those controlling who can order lab tests and those stipulating accreditation standards. Chair Lake, Dr. Burke and Dr. Miyamoto raised questions about the detail of the law on these issues, e.g. who can order additional testing on an existing sample, how are physicians who order tests identified. Staff will research this. Dr. Bereano noted that despite stringent HIV testing laws, many labs violate these. Dr. Burke suggested that it is important to distinguish between ethical laboratory practices that are internally created and enforced vs. those that exist in the law and determine how those are enforced. Dr. Burke made the point that solutions to problems of implementation of a law are not necessarily those that bring in new regulatory oversight. Dr. Bereano suggested that it is an issue of consent between the physician and the patient regarding what tests can be asked for.

Ms. Bennett asked if there were existing regulations regarding blood/tissue samples obtained for health/life/disability insurance. Staff will research this.

Kenneth Thummel, Ph.D.

Dr. Thummel testified and addressed the questions listed on the agenda. With respect to barriers to research, he identified an increasing regulatory burden. He noted that many researchers are accepting of the current framework including the stringent IRB approval process but there is a concern that there will be increasing oversight and paperwork required to continue to do research. If research on the relationships between polymorphisms and clinical outcomes is discouraged, there is a high likelihood that the public will undergo genetic testing with no idea as to what the results actually mean. This could potentially lead to the misuse of medications by patients and the misuse of information by lobbyists and policymakers. If research doesn't occur to clearly define these relationships, then the information can be manipulated to achieve ill informed ends. Dr. Thummel observed that currently, access to tissue/DNA isn't a barrier.

Questions/Discussion

Dr. Burke noted the difference between federally funded and privately funded research requirements with respect to human subjects protections in the form of IRB review. She asked Dr. Thummel what forms of additional consent (such as blanket consent or recontact authority)

might be appropriate for these types of studies. Dr. Thummel stated that the human subjects issues are the same for public and private research and there should be a common rule that applies to both types.

Dr. Miyamoto asked Dr. Thummel if he received any complaints about how DNA samples are used. Dr. Thummel indicated that he receives one type of complaint: research subjects may want their test results even after they agreed that they weren't going to get them. He has not received complaints about how a subject's DNA was used.

Dr. Callahan asked what additional state regulations would look like. Dr. Thummel suggested that new requirements for post-study follow up with subjects would constitute an additional burden. This is not routinely done with the healthy subjects/volunteers.

Dr. Scott, Dr. Bereano and Dr. Thummel discussed the possibility of creating different levels of consent for use of stored tissue for research that will associate genetic information with clinical information.

DISCUSSION II: FUTURE DIRECTIONS OF GENOMICS IN PUBLIC HEALTH PRACTICE

Panelists:

- Maxine Hayes, M.D., M.P.H., Health Officer, Washington State Department of Health
- Karen Edwards, Ph.D., Assistant Professor Department of Epidemiology, Director Center for Genomics and Public Health
- Amy Klein, M.P.H., Association of State and Territorial Health Officers, Director of Genetics

Maxine Hayes, M.D., M.P.H.

Dr. Hayes testified that only one of the questions on the agenda specifically relates to the public health community; public health tends to utilize research results, rather than doing research. She commented that the Human Genome Project, as well as other recent advances, present unique opportunities for public health. The long-term vision is to benefit the individual as well as promote population health. There is a strong reliance on science and prevention. Dr. Hayes suggested that genomics is to public health what infectious diseases used to be. Genomics is a tool for improving the health of populations; but public health will be significantly challenged to find optimal ways to integrate this new knowledge into existing public health infrastructure. Public health will rely on many partners to get it to a point of integration. First, human services must translate and disseminate bench science knowledge; examples of existing programs working toward this are the CDC's new program on Genomics and Disease Prevention, the National Center on Chronic Disease Prevention and Promotion, the Agency for Healthcare Research and Quality, three new University based genomics centers, and ASTHO. Dr. Hayes noted that the current mindset is different from the traditional role of genetics in public health with a shift toward realizing that all aspects of public health (access, assurance, and policy development) contain genetic-related components. For example, chronic disease planning must include genetics. Dr. Hayes identified several barriers to realizing the potential of public health genetics: the lack of leaders, tools, and a trained, competent workforce as well as the lack of flexibility of federal money at the state level. Dr. Hayes suggested that Washington state needs to update its genetics plan and think about genetics across all areas of public health; define a role for genetics in public health; and make policy decisions with how, what and when we implement those roles.

Karen Edwards, Ph.D.

Dr. Edwards testified that there are three new CDC-funded Centers for Genomics and Public Health, and one is at the University of Washington. The three centers currently serve all 50 states. The Centers' activities include: expanding the information base of genetics for public health; summarizing information about associations between the gene and the disease; identifying gaps in knowledge specifically for public health and making recommendations to the national level to suggest funding; and providing technical assistance to state government. The Centers must help get the public health workforce up to speed. Public health needs to shift toward integrating genetics into chronic disease prevention and away from newborn screening. One consideration is whether or not screening for chronic diseases will ever be integrated into newborn screening, and if so, what are the ethical and other issues involved in this. Also, state public health must decide if the use of banked blood spots for research is ethical. Dr. Edwards stated that new guidelines/policies must be consistent across states; disparate policies place different burdens on different states and will adversely effect the sharing of information across states.

Chair Lake inquired about concerns regarding how public health can realize its own promise through the use of genomics in the future. She asked if regulations would influence public health or population based research. Ms. Klein responded that one must consider the unintended consequences of limiting access to genetic information in terms of the role public health has in protecting people in other ways.

Amy Klein, M.P.H.

Ms. Klein addressed the question of where public health is going with genetics. She stated that genetic information could be used to prevent disease (determining prevalence; targeting at-risk populations/individuals). Public health can provide neutral information about genetics to interested stakeholders. There is a need to educate the public health workforce, build public trust, and to look outside the departments of health for what other public health providers can contribute. Ms. Klein identified some barriers to these goals such as the prohibition of the use of information to protect the health of populations because of restrictions and lack of translational research. She noted that incentives for public health include funding. One job of the public health infrastructure is to beta-test genetic developments; it has the capacity to apply these developments to a population other than the study population (i.e. not looking at benefits of individual intervention but rather looking at benefits of programmatic intervention).

Questions/Discussion

Dr. Bereano asked if restrictions on information could actually facilitate public health ends. He used restrictions on AIDS/HIV information as an example. People felt protected and therefore they pursued testing/treatment. Ms. Klein responded that the issue pivots on the critical point of sharing the information with whom. Dr. Bereano noted that there are no civil libertarian concerns with properly anonymized information.

Mr. Thorsen asked whether or not a correctly written informed consent agreement would facilitate the sharing of information. Dr. Edwards responded yes, but the concern is about additional restrictions with unintended consequences. If people are concerned about stigmatization, then the research cannot proceed. Ms. Bennett stated that data could be stigmatizing to a population, even if it is anonymized (e.g. associating particular genetic disorders with specific populations). Dr. Edwards suggested that it is important to educate people that disease is only at a higher rate in different populations, and that doesn't mean that the disease does not occur in other populations.

Dr. Burke asked if a researcher who had an idea for a project that required use of newborn blood spots would have to go through another type of approval at the state level separate from IRB approval. Dr. Hayes indicated that a researcher would have to go through additional levels of approval such as a review by program directors or health officers or the Secretary of Health.

Dr. Callahan asked if mandated collection of DNA for public health purposes was a potential future problem. Dr. Burke noted that mandated data collection is a different issue; it requires passage of a law, and an entire community process and Dr. Bereano noted that newborn screening is a large mandated collection program. Dr. Burke suggested the crucial question was what kinds of protections exist around any subsequent use of information collected for a specific public health purpose. Dr. Hayes stated that protections do exist.

Dr. Miyamoto asked the panel to define who is public health. He suggested that it is important to understand who constitutes the public health workforce so that we can plan for education about and addressing the issues arising from the genetics revolution. Dr. Miyamoto also stated that passing a law/regulation without understanding its effects is dangerous.

11:45 a.m.: Break for lunch and art gallery tour. The meeting reconvened 1:35 p.m.

DISCUSSION III: PRIVATE VENTURES IN GENOMIC DIAGNOSTIC AND TREATMENT TECHNOLOGIES

Panelists:

- Steven Gilbert, Ph.D., Director Institute of Neurotoxicolgy and Neurological Disorders
- Mr. Eric Earling, Director of Public and Government Affairs, Washington Biotechnology and Biomedical Association
- A. Bruce Montgomery, M.D., Ph.D., Chief Executive Officer Corus Pharma Inc.

The panel provided handouts supporting the discussion.

Mr. Eric Earling

Mr. Earling explained what biotechnology is and what the industry is like in Washington. He noted the size of the industry and its economic impact in Washington State. Mr. Earling stated that there are many challenges facing the biotechnology industry and he recommended that public policy should interact with industry by doing no harm. He distributed a document that outlines the Washington Biotechnology and Biomedical Association statement regarding preferred policy approaches. Mr. Earling's testimony addressed questions 2 and 3 on the agenda. Mr. Earling commented that biotechnology significantly impacts today's medical care; it is the new wave of treatment for diseases that are currently untreatable and it will provide more effective treatments than those that currently exist.

Dr. Steven Gilbert

Dr. Gilbert offered testimony from the business perspective. He noted that the presence of the biotechnology industry is important to local business. He also suggested that public education in the area is critical. Dr. Gilbert discussed the use of DNA chip technology; drug development changes that will save time and gain new possibilities for treating diseases; and gene array technology that gives information about gene expression that can be used for targeted treatment. Dr. Gilbert observed that the technology focus is shifting from hardware to software development; companies must be able to turn data into useful information. He discussed the promise of reducing the incidence of adverse drug reactions with tailored drug therapies and the

importance of sharing data within the industry. Dr. Gilbert stated that technology is currently pre-clinical but it is advancing quickly in the clinical area. Many studies are focused on the correlation of disease variables to specific genotypes. Dr. Gilbert showed data on the amount of money (approximately $200 billion) involved in research on medical diagnosis and monitoring. He suggested that the next ten years will bring significant advances in the field and that the ethical issues are enormous considerations.

Dr. Bruce Montgomery

Dr. Montgomery noted that the tools for genetic research are widely available and the cost of doing testing/sequencing is decreasing and the task is becoming easier. Dr. Montgomery discussed the issue that some commonly used drugs can lead to death if given to the wrong person and this may be influenced by the person's genetic makeup. Genetic profiles of individuals suffering adverse drug reactions can demonstrate that there is a problem with a drug class; predicting this can prevent severe/lethal reactions to medications. Drug/drug interactions can be lethal and combinations are not often tested in a clinical trial. He stated that 'genes weigh the dice' but do not necessarily provide a definitive answer about future disease status; other factors may contribute to adverse drug reactions and interact with drugs (e.g. alcohol). Also, knowing the risk of genetic/environmental interactions can be useful for people. If these can be predicted through the use of genetic information, health care costs can be reduced. The increasing cost of medications make a genetic test that can predict who a specific drug will work for appealing to insurance companies. Dr. Montgomery suggested that there is economic value in developing drugs that specifically target pathogens as this can save animal lives in trials and save time to development. Dr. Montgomery noted that many conditions are syndromes (many diseases lumped into one) and if these can be identified as separate diseases it can have treatment implications.

Questions/Discussion

Dr. Burke asked the panel to address the issue of labeling individuals with predictive genetic information. She suggested that in their future projections, it is not a question of whether or not people will be labeled, they will, but it is a question of whether they will be labeled for trivial reasons or for sound medical reasons. Dr. Montgomery responded that genetic testing should be used for 'beneficial labeling' by providing important health care information; it is the right thing to do to reduce poor outcomes. Dr. Burke commented that society should be prepared to decide on the appropriate non-medical use of the technology and information. Dr. Gilbert responded that it is unrealistic to think that genetic information won't be requested and that it won't be used; for instance the FDA is mandating more studies on drug interactions and in the future people will be tested before they are prescribed drugs.

Dr. Hayes asked the panel to address the commitment of the biotechnology industry to help sustain and fund the public health infrastructure and to bring the technology to the public health arena. Dr. Montgomery responded by describing his past experiences with developing treatments for diseases such as tuberculosis. He stated that short patent lives and long discovery times affect companies' ability to develop products. Investors take huge risks and don't get much of a return when companies try to cure third world diseases. Dr. Gilbert concurred that there is too much pressure on companies to turn a profit; investors are not willing to invest in social goals. The private sector is not a good place to try to develop unprofitable products; he suggested that there is a role for society and government to fund and support that type of research. Dr. Burke commented that in addition to getting benefits from drug development, there is a role for companies to participate in the appropriate use of the technology. Mr. Earling replied that many companies have a desire to do socially responsible research and product

development but the question is feasibility in setting up the infrastructure for active involvement in appropriate development. Dr. Montgomery commented that shareholders control the work done in companies, but personal money and time can be invested toward other goals and many CEOs do invest their personal time and money in this way.

Dr. Scott inquired about the differences between the review process that a private company must go through compared to a publicly funded research project with regard to IRB requirements for anonymous testing. Dr. Montgomery replied that almost every protocol he's worked on has been reviewed by a University IRB, the FDA, and/or a data safety monitoring board. He never has access to patient's names but he may have another coded identifier associated with a sample. Samples used in research are collected under IRB regulations and they are not able to identify individual subjects. He commented that private companies generally go to great lengths to remove identifiers from samples. He stated that private companies usually meet stricter requirements than universities because they have to go through multiple layers of approval or multiple IRBs. Dr. Gilbert added that different phase trials require different levels of review. This level of review costs a lot of money and companies are often able to do it more rigorously than academic researchers.

Dr. Callaghan asked if it was because companies seek FDA approval that they have to meet federal standards. Dr. Montgomery said it even goes beyond that because companies often have to meet very rigorous, sometimes more stringent international standards (e.g. EU standards). If a company violates a requirement, they run the risk of being shut down and put out of business. Inspections can be unannounced, so companies have to be prepared for an inspection at a moment's notice.

Chair Lake asked the task force to look at the blue sheet regarding policy options proposed by the WBBA. Dr. Callaghan asked about the 4th paragraph on policy statement. What is a burdensome law? Mr. Earling replied that HIPAA regulations and how they may affect patient care could be burdensome. He also suggested that a previously proposed state law that would have banned discrimination based on genetics would have been burdensome because it would have banned transmission of any genetic information related to health insurance; that is an example of a well-intended law that would have inadvertently affected medical research. Dr. Montgomery responded that a law that prevents the collection or processing of information about a genetic predisposition to adverse drug reactions creates a barrier to research. He has stopped doing research in some states that have overly restrictive policies. It is important for researchers to be able to go back and look at records after a study is completed without having to get consent again in order to look for adverse drug reactions and to maintain quality control. Mr. Earling suggested that policymakers need to ask if a new administrative burden adds benefit to the patient.

Ms. Bennet referred to page 6 of the blue handout and asked what happens to samples and data when a company goes out of business. Dr. Montgomery replied that there is a 5-year rule to maintain samples after which time they can be destroyed. Dr. Gilbert commented that some samples can be used to create banks. When companies close, they have to follow regulations to dispose of biological waste. Often, the old company is bought out and the new company becomes responsible for the tissue samples and data. Mr. Thorsen asked if samples are ever sold if a company is liquidated. Dr. Montgomery responded that the samples are usually not sold. Mr. Thorsen then inquired about why companies oppose legislation if the tissue is not of value. Mr. Earling replied that it's a question of the utility. Dr. Montgomery said that it is not the

monetary value but the hassle; raising the regulatory burden should have equivalent benefits to society vs. the risk of a rogue company misusing information.

Ms. Suiter asked the panel if there is anything they would like the task force to recommend at the state level. The panelists replied that it is hard to give a direct answer because there are strong federal regulations so there is a need to evaluate what the state could add to that. The industry feels that federal regulations provide adequate oversight and protection and that consistency in regulation is important or developers will move to where the process is easier.

Chair Lake led a discussion on ESSB 5207. Representative O'Brien explained that this bill changes the definition of health care information to include DNA and that because of this change; genetic information now has the same protections as other health care information.

The HIPAA update was postponed until the next meeting.

DISCUSSION OF NEW MATERIALS

Glossary

Regarding adding 'genomics' to the glossary, Dr. Burke commented that there is not necessarily an agreement over the difference between genetics and genomics but many people tend to use genetics in a traditional concept for single gene disorders and genomics to capture more complex genetic, gene/gene or gene/environment conditions, or a systems approach. Dr. Hayes suggested that genomics is information dealing with the entire genome; it is the total knowledge of the genome as opposed to just genetic variation; it is also the way of applying genetics as we apply epidemiology – across everything, as a tool in terms of using and promoting health and disease prevention. Ms. Bennett requested that the definition of emancipated minor in Washington be added to the glossary and a state and/or the ADA definition of disability be added as well.

Matrix

Chair Lake suggested that some changes might be necessary to the "includes exceptions for research" category after today's discussion. Dr. Burke suggested that information about the FDA regulations discussed today be added to the matrix. Dr. Bereano expressed concern that the matrix is at a level of generality that is not really helpful for drafting conclusions; more detail on certain topics (e.g. guidelines for IRB oversight) is necessary.

Drafting Conclusions And Recommendations For The Final Report

The rest of the meeting concerned different approaches to drafting conclusions and recommendations for the final report. After substantial discussion, the task force members agreed to divide into subcommittees to address the topics laid out in the legislative mandate. Each subcommittee will consider a specific way that genetic information is collected or used and write a report on its conclusions and recommendations related to the 4 areas outlined in the legislative mandate: a) The incidence of discriminatory actions based upon genetic information; b) Strategies to safeguard civil rights and privacy related to genetic information; c) Remedies to compensate individuals for inappropriate use of genetic information; d) Incentives for further research and development on the use of DNA to promote public health, safety and welfare.

The subcommittees and their members are as follows:

Subcommittee 1: Use Of Genetic Information In The Health Care Setting

C. Ron Scott (Subcommittee Chair), Robin Bennett, Robert Miyamoto, Maureen Callaghan, Julie Sanford Hanna

This subcommittee will look at three areas related to the use of genetic information in the health care setting: a) Diagnosis of symptomatic and asymptomatic conditions; b) Reproductive decisions; and c) Predictive identification of genetic risk factors for low penetrant diseases.

Subcommittee 2: State Mandated DNA Collection/Genetic Testing

Maxine Hayes (Subcommittee Chair), Phi Bereano, Brenda Suiter, Howard Coleman, Suzanne Plemmons

This subcommittee will look at the existing systems for state mandated DNA collection and/or genetic testing (Newborn Screening Program and forensic uses of DNA). This includes an analysis of the DOH privacy policies regarding the Newborn Screening Program.

Subcommittee 3: Research

Helen McGough, Peter Byers, Phil Bereano, Amanda DuBois, Vicki Hohner (this subcommittee does not yet have a chair)

This subcommittee will look at the use of genetic information in academic/basic science, public health, and biotechnology industry research.

Subcommittee 4: Other Social Uses Of Genetic Information Including Health/Life/Disability Insurance And Employment

Mellani Hughes (Subcommittee Chair), Ty Thorsen, Wylie Burke, Nancy Fisher, Joe Finkbonner

This subcommittee will look at the use of genetic information for social purposes such as health/life/disability insurance and employment.

Chair Lake adjourned the meeting at 4:35 p.m. The next GTF meeting is scheduled for June 25, 2002.